



Every Woman's Life

Community Health Worker Training Manual

Funded by: Virginia Department of Health through a grant from The Centers for Disease Control and Prevention

The **Every Woman's Life program**, also known as the **Breast and Cervical Cancer Early Detection Program (BCCEDP)**, operates under the Breast and Cervical Cancer Mortality Prevention Act of 1990, Public Law 101-354. It authorized the Centers for Disease Control and Prevention (CDC) to develop and implement a national program to ensure that every eligible woman receives regular screening tests for breast and cervical cancer, and prompt follow-up when necessary.

National legislation does not directly permit payment for cancer treatment with CDC funds. Virginia BCCEDP does not pay for cancer treatment with CDC funds. However, the Breast & Cervical Cancer Prevention and Treatment Act of 2001 permits women who have been enrolled in the Virginia BCCEDP and diagnosed with breast or cervical cancer by one of our providers to be enrolled in the state Medicaid program for payment of treatment services. Ongoing activities of state, community and local coalitions have also identified resources and networks of generous providers who ensure women receive needed treatment.

Virginia is one of over 70 state, territorial and tribal organizations that received funding from the CDC to implement a comprehensive breast and cervical cancer detection program for women. All women will be screened for eligibility prior to enrollment in the EWL program. Eligibility will be determined annually. The following are the requirements for eligibility to receive EWL funded services:

- a. Female gender (self-declared)
- b. Age – must be age 50-64
- c. Income must be 200% of the Federal Poverty Level or
- d. Primary residence in Virginia
Uninsured or underinsured

Women in the priority population, 50 to 64 years of age, minority, rarely or never been screened (never had a Pap test or have not had a Pap test in the last 5 years) face the following barriers to screening: fear of discovering cancer, the costs of services, lack of transportation, lack of physician referral, communication barriers, and lack of child care. The National Breast and Cervical Cancer Early Detection Program provides resources to remove these barriers, establish greater access to screening and follow-up services, increase public education and outreach activities and provide case management services.

The hope is that you, as a Community Health Worker (CHW) can further strengthen the breast and cervical health outreach component of EWL in communities because of your energy, initiative and commitment. You can “break the silence” around breast and cervical cancer, leading women to have mammograms and Pap tests.

Building the Bridge



Community Health Workers serve as the link or the "the information highway" between the community and the Every Woman's Life program. There are many qualities and characteristics that a CHW needs in order to really be a bridge between her community and the provider site. Some are shown in the box below.

Characteristics of a Good CHW

- good listener
- trusted by others
- respected by others
- respects others
- responsive to the needs of others
- interested in women's health
- caring and compassionate
- maintains close and supportive relationships with others
- a good communicator
- a good motivator
- understands how to access the health care system
- can balance the demands of community lay outreach working and other responsibilities

How Do These Compare?

For White women, 140.8 people get breast cancer in a year.



For African American women, 121.7 people get breast cancer in a year.



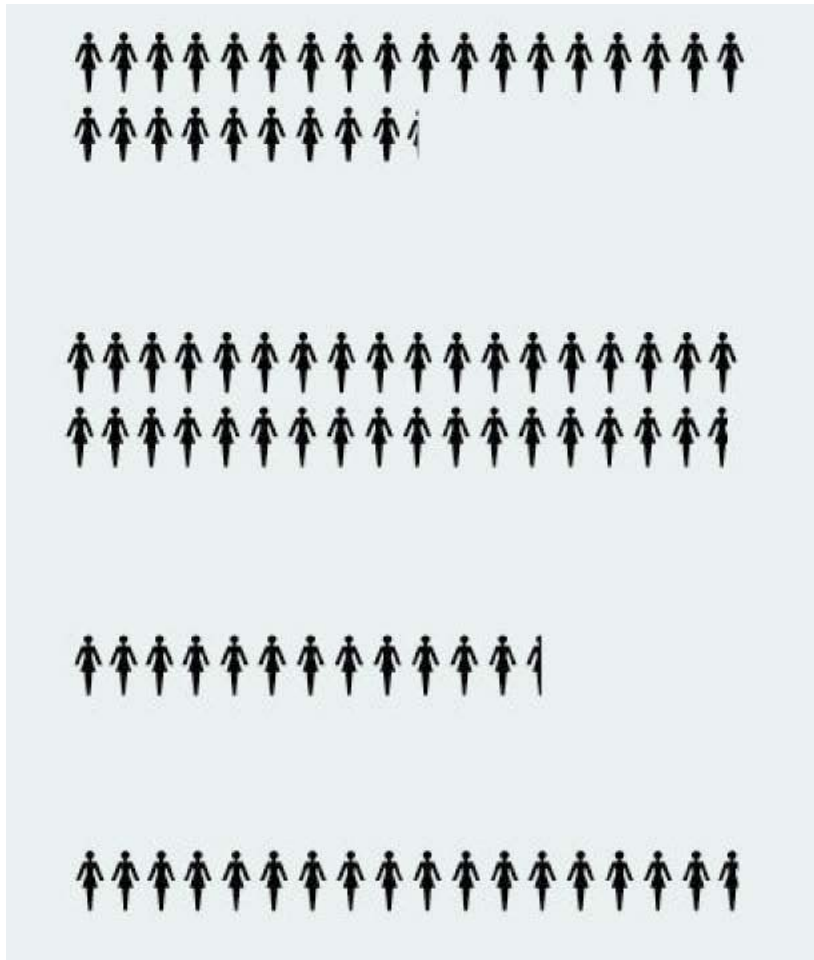
For Asian women, 97.2 people get breast cancer in a year.



For Hispanic women, 89.8 people get breast cancer in a year.



Now let's look at how many White women, African American women, Asian women and Hispanic women are dying from breast cancer.



Out of 100,000 White women,
27.2 people died from breast cancer.

For African American women, 35.9
died from breast cancer.

For Asian women, 12.5 died from
breast cancer.

For Hispanic American women,
17.9 died from breast cancer.

Source: SEER Cancer Statistics Review 1975-2000, National Cancer Institute. <http://seer.cancer.gov>

When we talk about who dies from breast cancer, how do the numbers of African American, Asian and Hispanic compare to those of White women?

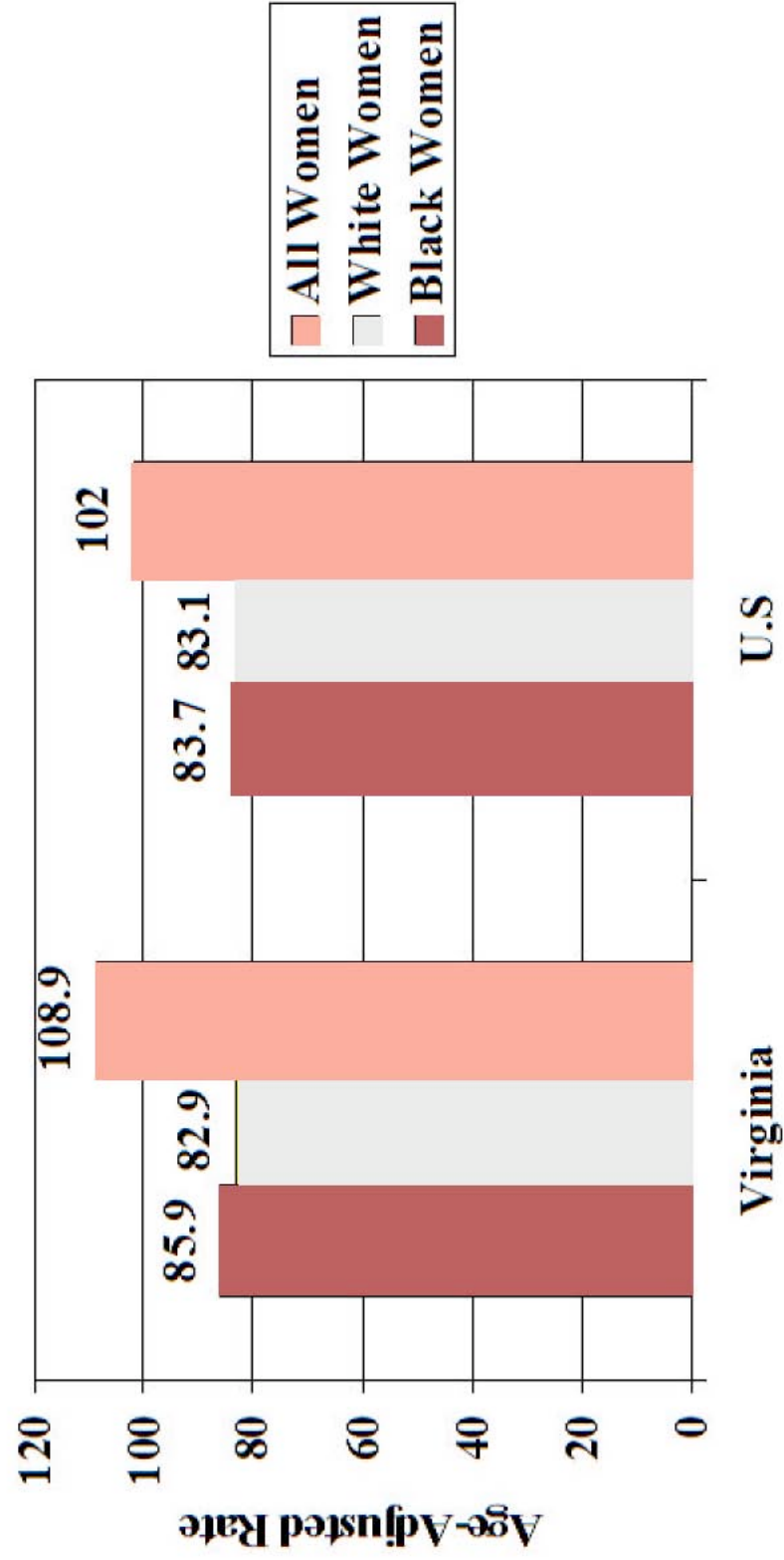
More African American and Hispanic women are dying from breast cancer than White women are. But, remember how many women got breast cancer.

Virginia Breast Cancer Incidence Rates by Top 10 Health Districts

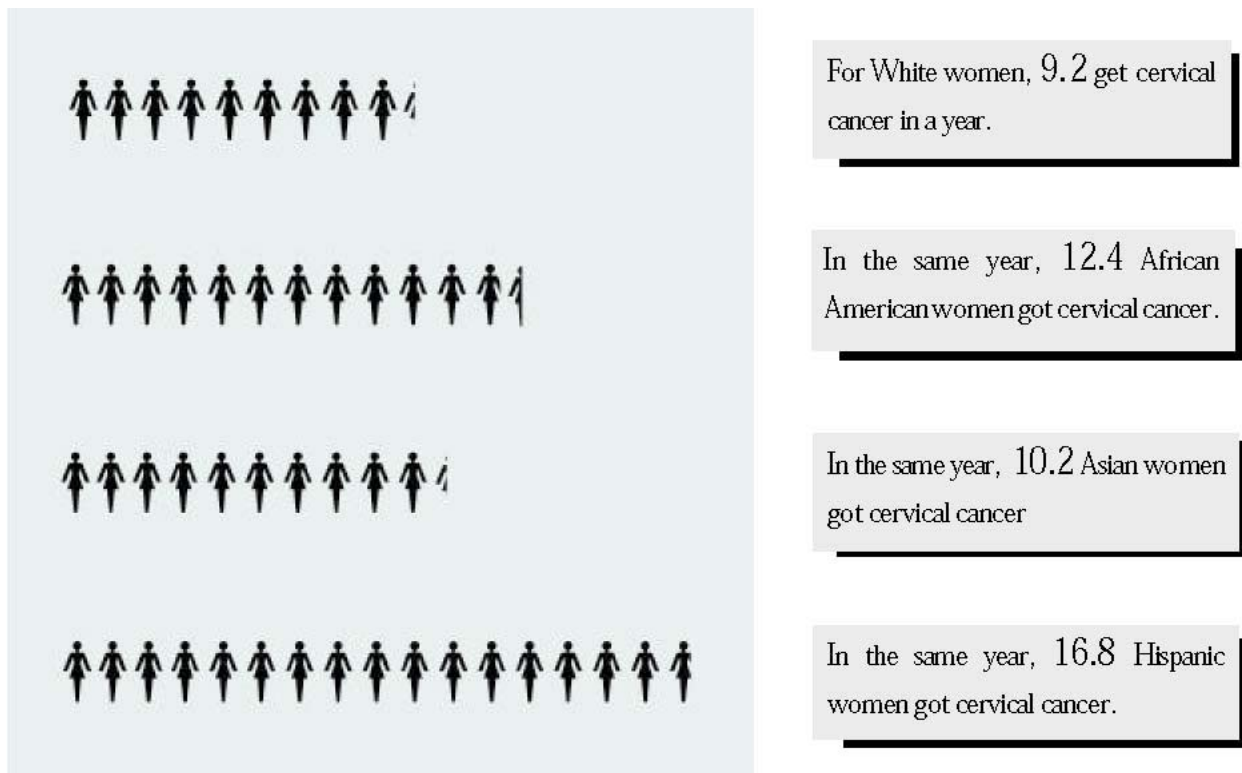


Virginia Cancer Registry 1995-1999
 Age-Adjusted Rate per 100,000 People (by the 2000 US Standard)

Breast Cancer Mortality Rates, Women Age 50+, Virginia and U.S., 1996-2000*



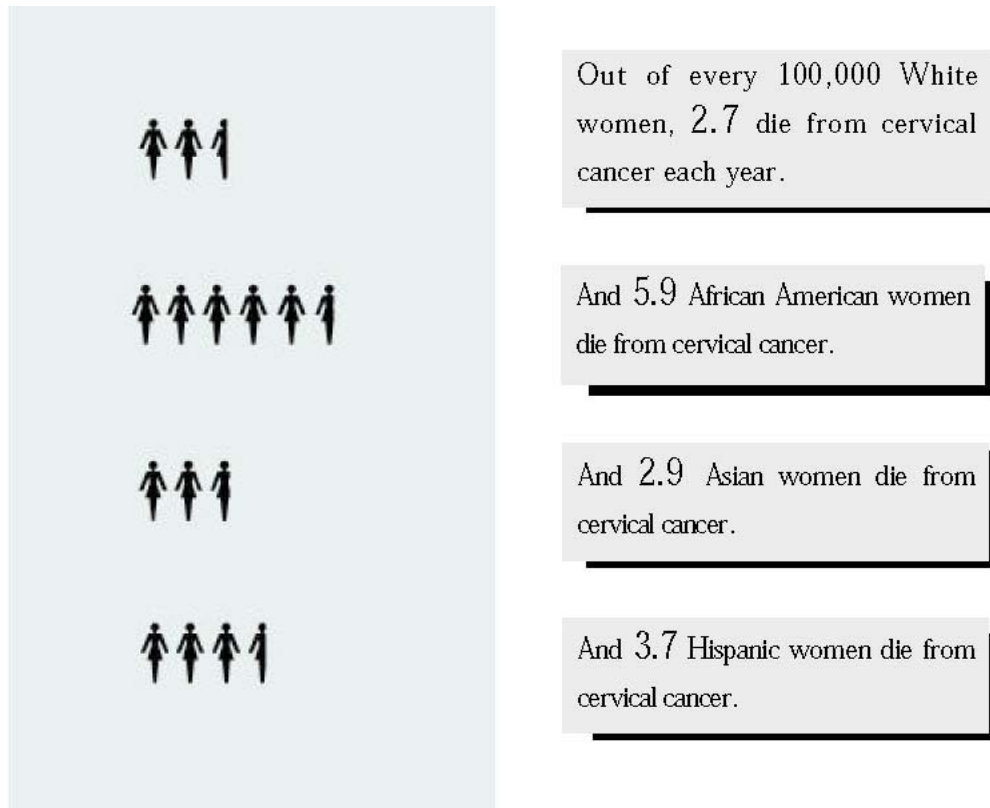
Now we'll look at the rates for cervical cancer and the differences among White women, African American women, Asian women and Hispanic women.



Source: SEER Cancer Statistics Review 1975-2000, National Cancer Institute.
<http://seer.cancer.gov>

You can see that cervical cancer affects fewer women than breast cancer in all the populations represented here. You can also see that African American women and Hispanic women are a little more likely to get cervical cancer than White women.

Now let's look at how many women in these racial/ethnic groups die from cervical cancer.



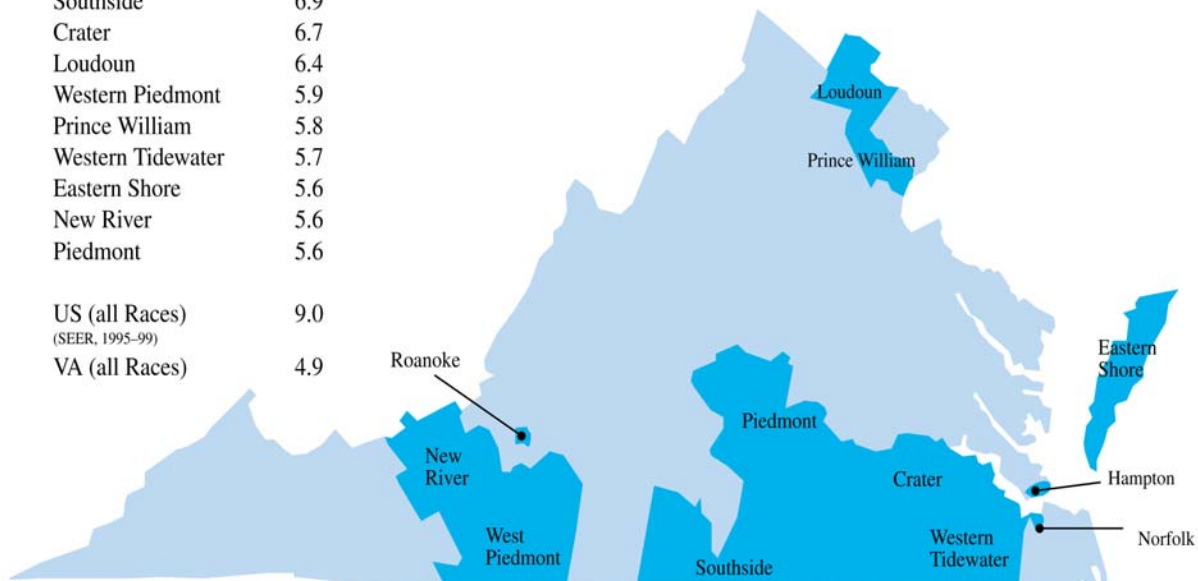
Source: SEER Cancer Statistics Review 1975-2000, National Cancer Institute.
<http://seer.cancer.gov>

What do you notice about the differences between breast and cervical cancer deaths? It doesn't look like many people die from cervical cancer, especially compared to breast cancer. But, it is important to notice that African American women are twice as likely to die from the disease as White women.

Virginia Cervical Cancer Incidence Rates by Top 12 Health Districts

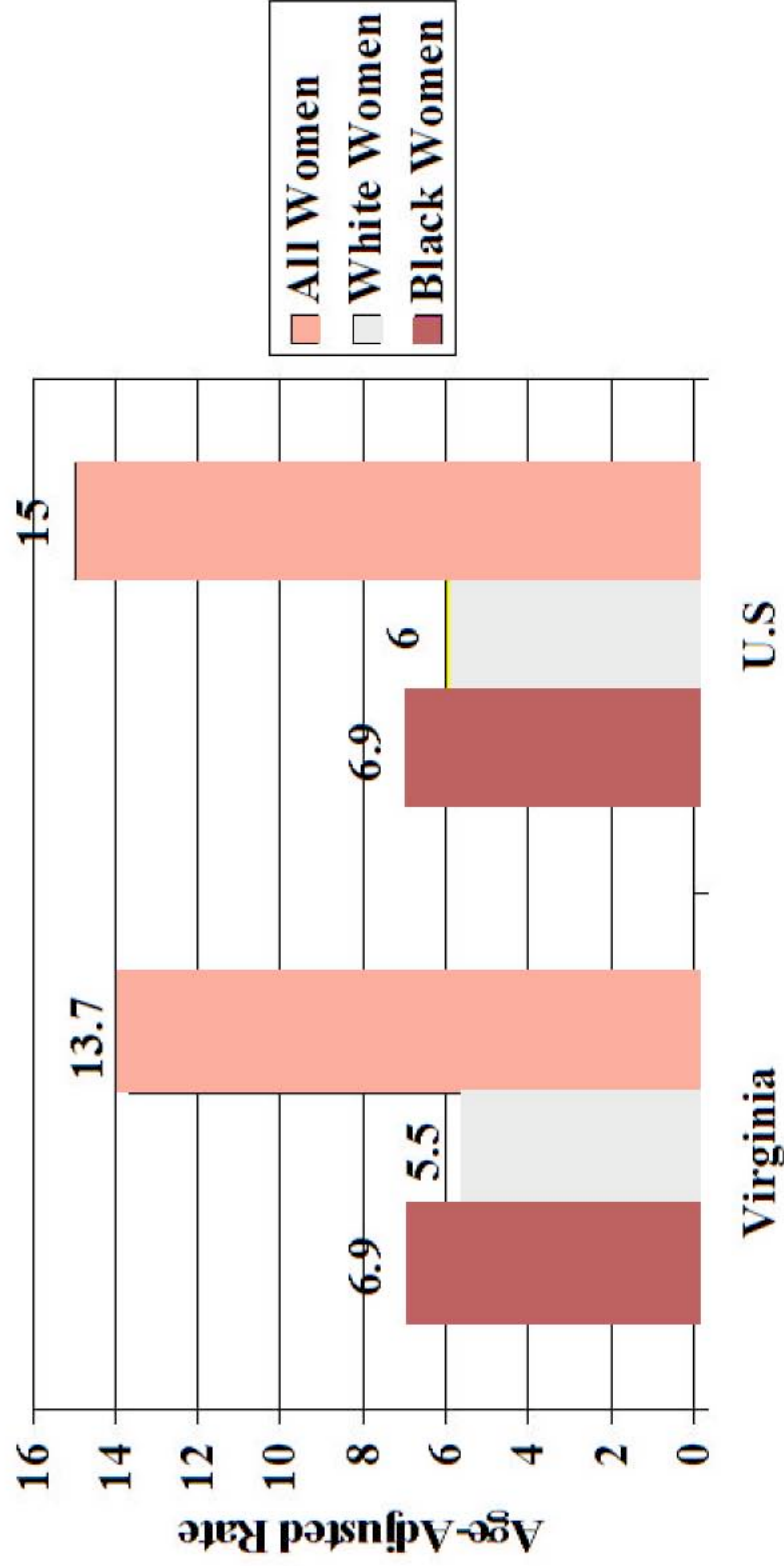
Hampton	7.7
Norfolk	7.5
Roanoke	7.4
Southside	6.9
Crater	6.7
Loudoun	6.4
Western Piedmont	5.9
Prince William	5.8
Western Tidewater	5.7
Eastern Shore	5.6
New River	5.6
Piedmont	5.6

US (all Races) (SEER, 1995-99)	9.0
VA (all Races)	4.9



Virginia Cancer Registry 1995-1999
Age-Adjusted Rate per 100,000 People (by the 2000 US Standard)

Cervical Cancer Mortality Rates, Women Age 50+, Virginia and U.S., 1996-2000*



* Data (1996-2000) provided by US National Center for Health Statistics. Rates are cases per 100,000. Rate is age-adjusted to the 2000 U.S. standard population.

If breast and cervical cancers are found early and treated, lives are saved. With both breast and cervical cancers, there are things women can do to lower the chances of getting and dying from them. The most important thing women can do is to get regular mammograms and Pap tests. These screening tests can notice breast and cervical cancer early while tumors or cell changes are small and easier to treat.

Risk factors are things that increase the chances of getting cancer; they can include who we are (heredity) and what we do (behavior). Other factors to consider include race and income. Poor women, no matter what their race, are more likely to die of breast cancer than are women with higher income because they lack access to regular health care, which includes screening for breast cancer.

Cervical Cancer

The list of risk factors for cervical cancer includes several that have to do with sexual behavior. That is because the Human Papillomavirus (HPV), a virus that is usually transmitted through sex, is present in 99% of cervical cancer cases. HPV is extremely common.

A few types of HPV can cause cells in a woman's cervix to grow abnormally and become cancer cells. It is important to remember that although a lot of women have HPV, only a small percentage develops cervical cancer.

HPV is the reason that sexual activity is a risk factor for cervical cancer. HPV is usually transmitted during sex. Since the virus is so common, everyone who has ever had sex is at some risk of having HPV.

Having several or more sex partners throughout your life or having a partner who has had several or more partners increases a person's chance of HPV infection. Girls who have sex at an early age are at high risk for getting HPV because their cervixes are still developing and more susceptible to infections.

Any woman who is or has ever been sexually active may have been exposed to HPV, which puts her at risk for cervical cancer. Basically, just about all women are at risk for cervical cancer even if they are no longer sexually active or are in a monogamous relationship.

Risk Factors

What are risk factors for
BREAST CANCER?

- Age (being older than 40)
- Being a Woman
- Smoking
- Mother, daughter, sister with breast cancer (family history)
- Start menstruating early (before age 12)
 - Never having children
- Having first child after age 30
 - High fat diets
- Being greatly overweight
 - Not breastfeeding

What are risk factors for
CERVICAL CANCER?

- Being a woman
- Smoking
- Family history
- Having HPV infection
- Being sexually active
- Multiple sexual partners
- Early first intercourse
- Not getting regular Pap tests

What are risk factors for
**BOTH BREAST &
CERVICAL CANCER?**

- Being a woman
- Smoking
- Family History



Breast and Cervical Cancer Basics

- Cancer occurs when cells in one part of the body grow without control or order
- Over time, the cancer cells can spread to other parts of the body
- Often breast and cervical cancer do not have any visible symptoms
- Mammograms can detect breast cancer early - before a woman is able to notice any signs or symptoms
- Pap tests detect abnormal cells and cancer cells in the cervix. In fact, Pap tests can find a problem before cancer develops.
- Mammograms and Pap tests save lives

What information here is new or surprising to you?

What similarities are there between the two lists?

What about differences?

How do these lists make you feel?

Breast Cancer

Most important risk factor is age. As a woman ages, her risk of getting breast cancer increases.

Minority women are less likely than White women to get cancer.

But, minority women are more likely to die from breast cancer compared to White women.

Cervical Cancer

Most important risk factor for cervical cancer is human papilloma virus (HPV).

HPV is very common. Many women have HPV and do not know it. It is usually passed through sexual contact.

African American women in Virginia are two times more likely to die from cervical cancer compared to White women.

Cervical cancer can be prevented.



Early Detection of Breast Cancer

Mammograms

Sometimes women experience some discomfort when getting a mammogram. Methods such as taking a pain reliever before the mammogram, practicing relaxation techniques, or talking to the technician are some options to take to overcome anxiety and physical discomfort.

What happens during a mammogram procedure? Before the mammogram, a woman is asked to remove clothing from the waist up and is asked to place one breast on a small platform. Then, a device called a paddle, which is lowered onto the breast from above, compresses the breast. With the breast squeezed between the platform and paddle, a woman holds her breath, the x-ray picture is taken, and the paddle is immediately released. The breast is then repositioned, the paddle is lowered, and another picture is taken. This procedure is then repeated on the other breast.

Some women require a modified procedure if they are in a wheelchair or otherwise unable to stand at the machine. A woman with disabilities may need assistance or extra time undressing, for instance. It is always a good idea for women with such limitations to ask when they schedule their appointment, if the facility can accommodate their special needs.

So who should get mammograms?

At age 40, women should begin to have a mammogram every year. Women who have a higher than average risk of developing breast cancer may benefit from starting early detection practices at a younger age or having additional tests or more frequent examinations. It is important to talk to your provider to find out what is best for you. Women with disabilities should follow these same guidelines, unless instructed otherwise by their physician.

Tips For A BETTER MAMMOGRAM

Bring a list of the places, dates of mammograms, biopsies, or other breast treatments you have had before.

If you have had mammograms at another facility, you should make every attempt to get those mammograms so that they are available to the radiologist at the current examination.

On the day of the examination, do not wear deodorant; this can interfere with the mammogram by appearing on the x-ray film as spots.

If your breasts are tender the week before your period, you should avoid mammograms during this time. The best time for you to have a mammogram is one week after your period.

You should describe any breast symptoms or problems that you are having to the technologist performing the examination. Be prepared to tell the person doing the mammogram (mammography technologist) about hormone use, family or personal history of breast cancer, and any prior surgeries. You should also discuss any changes or problems in your breasts with your doctor or nurse before having a mammogram.

If you do not hear from your doctor within 10 days, do not assume that your mammogram was normal -- call your doctor or the facility.

For more information about mammograms, finding breast cancer early, or about breast cancer, please contact your American Cancer Society at 1-800-ACS-2345 day or night, or visit their web site at www.cancer.org

There are other ways that some breast lumps can be detected, and these can be part of regular preventive health efforts. They are discussed below and are based on the American Cancer Society guidelines (2003).

Examining the Breasts

Breast cancer will sometimes, but not always, be found by breast self-exam (BSE) or clinical breast exam (CBE) by a doctor. But in order to save lives, the exams must find the breast cancer as early as possible. During a clinical breast exam, the nurse or doctor feels the breast and underarm with the fingers to check for lumps and other changes. Women should have a clinical breast exam with each routine checkup or annual gynecological exam.

BSE can help you become familiar with how your breasts normally feel. Knowing what is normal for you is important so that if you notice a difference at any time (dressing, bathing, etc.) you can contact your doctor. If you choose to do BSE, the health professional you see for regular care can show you how, check to see that you are doing it correctly, answer any questions, and explain the importance of promptly reporting any new breast symptoms or problems. It is also okay to choose not to do BSE, or to do BSE but not every month.

The number one thing a woman can do to lower the risk of dying from breast cancer is to get a regular mammogram. But, other than having a mammogram, how can a woman suspect breast cancer? 1) a lump, 2) a recently inverted nipple, 3) nipple discharge, 4) dimpling of the skin or 5) skin that looks like an orange peel

These are possible signs of breast cancer, but not definite ways of knowing. While these are possible signs of breast cancer, in many cases there are no visible signs or symptoms. In fact, by the time there are symptoms, the cancer is often very advanced and more difficult to treat. The best way to protect you from breast cancer is to have a mammogram. And because cancer can develop slowly over time or suddenly, even after you get a mammogram, it's important to get them on a regular basis.

Mammography is the MOST important detection tool, then CBE, and lastly BSE because the size of the lumps that can be felt with BSE.

Self-Examination

A breast self-exam is similar to a clinical breast exam but in this case a woman is feeling her own breasts and underarms to check for lumps or other changes. Women can do breast self-examination to become familiar with the usual appearance and feel of her breasts. A breast self-exam has two parts: Looking and Feeling.

Looking

Stand in front of a mirror and look at your breasts. No one's breasts are both exactly the same. Look for anything unusual such as puckering, discharge, changes in color or shape and look using 3 poses:

- Arms hanging at your sides

- Hands over your head

- Hands on hips, shoulders rolled forward

Feeling

While standing, feel each breast, one at a time: 3 fingers, 3 circles, 3 pressures. Using the flat part of three fingers, begin in your armpit. Press gently in a small circular motion - pressing lightly, medium and deeply. Feel through the entire thickness of the breast. Move the fingers down slightly and repeat 3 circles, 3 pressures. Continue to move your fingers down so you cover the entire area from your collarbone to your bra line and from armpit to chest bone.

Early Detection of Cervical Cancer

Pap Test

A Pap test is an examination of the cervix to look for cancer or any changes in the cells that may lead to cancer. Getting a Pap test is important because it is the only way to tell if a woman has cervical cancer. It can also detect changes in the cervical cells that may lead to cancer, and allow a woman and her doctor to take steps to prevent it.

Cervical cancer is unique in that it is almost totally preventable and treatable if found early.

During a Pap test, a woman lies down on her back on the exam table and puts her feet in the stirrups. The doctor or nurse then inserts a speculum into her vagina in order to see into the vagina. The speculum is lubricated and may be uncomfortable, but it should not hurt. The doctor or nurse then uses a tiny instrument to take a few cells from inside and outside of the cervix. They will then place the cells onto a glass slide, and it will be sent to a laboratory to be checked for cancer or other problems.

All females should begin getting Pap tests within 3 years after vaginal intercourse, but no later than age 21 (American Cancer Society, 2002)

Routine Pap screening is recommended at least every 3 years for women who have not had their cervix removed, with frequency based on risk factors (US Preventive Services Task Force, January 2003).

Pap screening can be discontinued after age 65 for women who have had adequate recent screening with normal Pap tests and are not at high risk; or women who have had a total hysterectomy for non-cancerous disease (US Preventive Services Task Force, January 2003). Pap screening can be discontinued age 70 or older, if at least 3 normal test results and no abnormal results in 10 years or in women who have had a total hysterectomy with removal of the cervix (American Cancer Society, 2002).

Breast Cancer and MAMMOGRAPHY	<ul style="list-style-type: none"> - African American women are less likely to get it, but more likely to die from it than White women - It is more common in older women than younger women - Women age 40 should start getting one every year
Cervical Cancer and PAP SCREENING	<ul style="list-style-type: none"> - African American women are more likely to get it and more likely to die from it than White women - HPV is a risk factor - All women should begin getting them within 3 years of vaginal intercourse or no later than age 21 - All women should get one even if they are not sexually active
Both Cervical and Breast Cancers/ MAMMOGRAPHY /PAP TESTS	<ul style="list-style-type: none"> - It can be detected early - It can be treated - Family history is a risk factor - A woman can have it and not know it because there might not be any symptoms - A woman should get one even if she feels healthy

Possible Barriers to Screening

- | | |
|---------------------------------|---------------------------------------|
| -fear of finding cancer | -lack of knowledge |
| -cost | -discomfort/pain |
| -time | -not having any symptoms |
| -transportation | -not having a doctor's recommendation |
| -embarrassment | -fear of radiation |
| -gender of health care provider | |

Communication Guide

When providing information about breast and cervical cancer, it is important to help women feel comfortable talking.

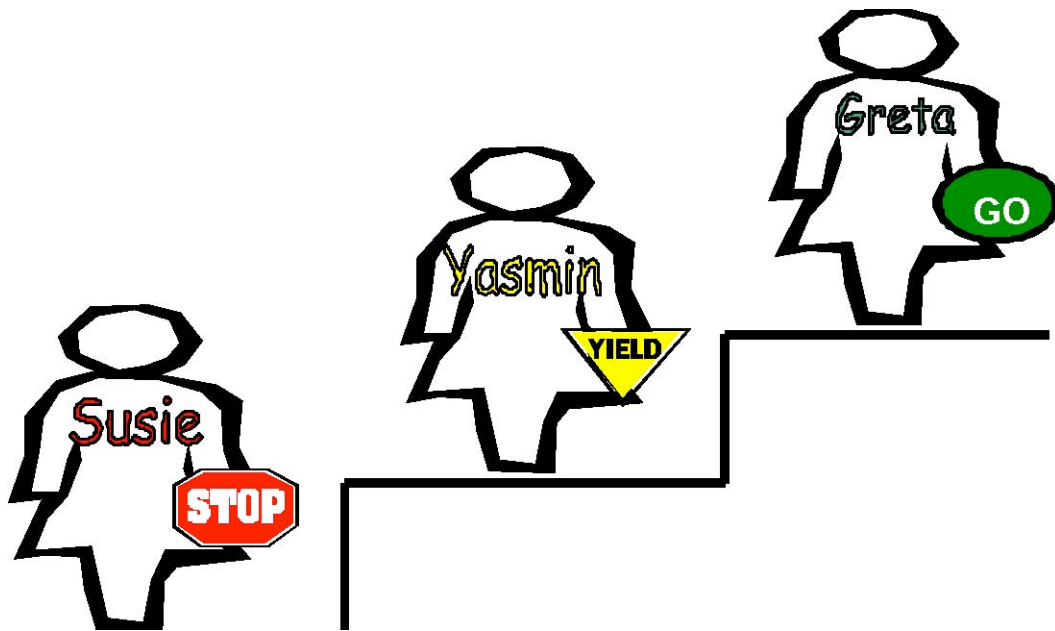
Things we can do to help women feel safe:

- Make eye contact
- Use "open" body language like leaning forward when listening and leaving arms open (not crossed)
- Speak gently and slowly
- Pause and give her time to think about what she wants to say
- Stand or sit close
- Touch her arm, knee or shoulder

Things we can say to help women know that we care:

- Encourage talk with simple phrases like "yes," "OK," "I see"
- Summarize important points
- Tell her that you respect her feelings
- Use "I" language to let her know you understand what she is feeling "I sense you are unsure." "It sounds like you're feeling frustrated."

Screening Exams: Stop, Yield or Go?



There are three important ladies for you to meet: **Susie STOP**, **Yasmin YIELD** and **Greta GO**. As you begin learning a little bit about each of them, you will probably realize that you know women just like these three.

Susie STOP is the woman holding the red STOP sign. She is 54 years old and has never been screened. What do you think Susie thinks about mammograms?

Susie doesn't really think about having a mammogram, which is why she is holding the STOP sign. It helps you remember that women who don't think about having mammograms are at STOP for the behavior. Basically, Susie is at STOP because she doesn't know why she should get a mammogram. If you know someone like Susie, what reasons does she give for not getting a mammogram?

Some reasons to think about are:

- not knowing what mammogram tests are for
- not knowing why mammograms are important
- believing that a mammogram is only necessary for women with symptoms
- being worried that a mammogram can cause cancer
- believing that cancer is always fatal
- not hearing from her doctor that she should get one (particularly a problem for women who see specialists instead of general practitioners)

Now let's meet **Yasmin YIELD** who is 50 years old. She is the woman holding a yellow YIELD sign. What do you believe Yasmin thinks about mammograms?

Yasmin is considering going for a mammogram. That's why she is wearing the YIELD sign. It helps you remember that women who are thinking about getting a mammogram but haven't gotten one yet are not at STOP but they aren't at GO either. Unlike Susie, Yasmin may know that mammograms are important. Certain things keep her from going for a mammogram. Yasmin is at YIELD because of barriers. She knows the good things about mammography- it's the barriers or bad things that keep her from going. If you know a woman like Yasmin, what reasons does she give for not getting a mammogram? Some reasons could be:

embarrassment about the procedure worry about it being painful cost/not enough money doesn't have time worried and afraid about what she might find too much hassle to deal with right now not knowing where to go not knowing about mammography facilities that are specially equipped for women with disabilities

Greta GO, age 63, is at the top of the steps. She's got the GREEN GO sign. What does Greta think about mammograms?

Greta is different than Yasmin because she doesn't just think about going for a mammogram—she gets mammograms! The Green light on her shirt tells you that she is going for mammograms. Why is Greta going for mammograms? Are you or someone you know like Greta? Women like Greta GO for mammograms because they know why they are important and are able to overcome all the hard things that keep them from getting them. We want to get all women to be like Greta and GO for mammograms.

Let's talk about Susie STOP, Yasmin YIELD and Greta GO's mammography behaviors again. Susie does not think about getting a mammogram. She's at STOP for this behavior. Greta is getting mammograms regularly. She's at GO for mammography. What about Yasmin? Yes, she is thinking about getting a mammogram. She's not at STOP like Susie because she's thinking about getting one but she's not at GO like Greta either. So now we've got Susie on the bottom step, Yasmin in the middle and Greta on the top step.

We've just described the different stages women can be in for mammography. These stages also apply to Pap screening. The decision to do something new or to repeat a behavior, like going for a Pap test, happens over time, in stages or STEPS. Knowing that there are STEPS to going for a Pap test helps you understand why it takes a long time to convince some women to go. And why with other women, it takes only a few words of encouragement or giving them a ride to the doctor's office.

Now, let's think about how to figure out whether a woman is at the STOP, YIELD, or GO STEP for mammography and Pap test screening. What are some of the things you would say to a woman to find out what STEP she is on?

Here are some helpful hints for identifying a woman's STEP. To find out if a woman is at STOP for mammograms or Pap tests, ask her if she knows. The key word to listen for with a Susie STOP is no. To find out if a woman is at YIELD for either behavior, ask her if she does. The key words to listen for with her will be if, but, or maybe. A woman who is at GO will answer yes to both questions.

Even though you will be talking to women about both mammography and Pap test screening, you will need to figure out what STEP a woman is in for mammography and what STEP she is in for Pap test screening separately. This is because a woman may be at STOP for Pap test screening but at GO for mammography. Trying to figure out what STEP she is in for both behaviors at the same time is too confusing. Pick mammography or Pap test screening, figure out what STEP she is in, and advise her about that. Then move on to the other behavior.

Learning Activities

So, how do we get clients to go!? The first thing we need to understand is how people make decisions. Think about decision making as a double-sided scale. A scale measures the weight of the pros and cons for getting a mammogram or Pap test. Pros are the good things people believe about a behavior. Cons are the bad things people believe about a behavior. People's decisions reflect which they think weighs more, the pros or the cons.

Decisional balance is an important part of the STEPS we talked about earlier. Let's think about women at STOP. So far, we know that they are not thinking about getting mammograms and some of the reasons why, including not knowing about the importance of mammograms or who is at risk for breast cancer. Women at STOP don't know any of the good reasons or pros for getting mammograms. For women at STOP, the CONS weigh much more than the PROS because there aren't any PROS to balance out the CONS. As you may have already guessed, this has a lot to do with why she is at STOP for mammography. Since she doesn't know any of the good reasons for getting mammograms, we can't possibly expect her to think about getting one.

Now we'll talk about women at YIELD. A woman at YIELD has thought about the pros for mammography. These women believe there are good things about getting mammograms, such as finding cancer early, peace of mind, and taking care of her health so she can take care of others. But they also believe that there are bad things or hassles involved, like inconvenience, pain, money, or worry about finding a problem. This is why women at YIELD are thinking about getting a mammogram but are not committed to getting one yet.

Learning Activities

Women who are at GO believe the pros or good things about getting mammograms weigh more than the CONS. That's why women at GO are going for mammograms. Women at GO know the benefits outweigh any possible disadvantages.

Many of you are wondering what all this information about the pros and cons means. At each STEP, you as CHWSs can use what you know about which weighs more, the pros or the cons, to advise women about mammograms and Pap tests. To move women closer to GO, you must give women information that helps tip the scale in favor of the pros.

Now we are going to talk about how we can increase the weight of the pros at each "step". We'll start with women who are at STOP. For women who are at STOP, the CONS are heavier than the PROS. How can we increase the weight of the pros? We need to tell her all about the good reasons to get a mammogram. When you meet a woman at STOP, you will WITNESS to her about the pros of mammography. When I say WITNESS about the pros of mammography, I mean tell a woman about your experience with mammograms, and personal stories about how it changed your life. You can share personal stories you've heard about how mammograms can save lives. Can anyone share some examples of WITNESSING about the benefits of mammography with the group? An example of WITNESSING: "I get mammograms because they keep me healthy for my husband and children. I've got a lot to live for and so do you."

Women at YIELD give equal weight to the pros and cons of mammography. They know the benefits already, but as a CHW you can help decrease the cons. When you meet a woman who is at YIELD, you can LIGHT THE WAY about overcoming barriers. LIGHTING THE WAY means identifying what a woman believes is keeping her from getting a mammogram and helping her find ways to overcome those obstacles. One example would be telling a woman who worries that mammograms are too expensive about the Every Woman's Life program, which helps women who can't afford to get a mammogram get one. An example of LIGHTING THE WAY: "I know it's hard for you to get to a mammography center, but if you tell me when you need to be there I'll be happy to take you."

Women at GO know the pros outweigh the cons. You don't need to change this! Instead, you should PRAISE them about how they are getting mammograms because it's easy to backslide! A woman may delay because she's busy and before she knows it one or two years have passed and she hasn't been back for a mammogram. Encourage women who are at GO to stay on schedule. Does anyone have an example of what PRAISING would sound like?

Helpful Hints for Staging Women

If you are talking with a woman about getting a mammogram or Pap test, it is important to ask the right questions and to really listen to what she is telling you about her behavior and the reasons she may or may not be getting them. Here are some key questions to ask and key words you can listen for to help figure out a woman's stage of change.

Ask if she knows... Do you know about mammograms and Pap tests?

KEY WORDS: "No," "Don't Know"

Susie needs information and facts.



Ask if she goes... Do you get mammograms and Pap tests?

KEY WORDS: "If," "But," "Maybe"

Yasmin needs help overcoming barriers



Ask if she goes... Do you get mammograms and Pap tests?

KEY WORDS: "Yes," "Definitely"

Greta needs praise for her healthy actions



Test Your Skills: Character Scenarios

“No Way Nora”

CHW: (Use conversation starter to introduce self to "advisee", try to figure out STEP for Pap test screening)

Nora: I'm not interested in hearing anything about Pap tests. Isn't that the test that they do to tell you if I have cancer or not? Now, why would I want to know if I have cancer? That's like telling me I'm going to die. If I'm going to die, I'd rather not know before hand.

CHW: (Advise based on what Nora told you)

Note to facilitator: CHW should be witnessing about the Pros of Pap test screening to Nora. She is obviously at STOP for Pap test screening. CHW could remind Nora that the earlier cancer is found, the easier it is to treat. Finding cancer early through a Pap test greatly increases your chances of beating it. CHW could also point out that finding cancer early through a Pap test is important to do for your family since they care about you and need you to be healthy.

“Embarrassed Emily”

CHW: (Use conversation starter to introduce self to "advisee", try to figure out STEP for Pap test screening)

Emily: I know I need to get one, but I just can't. I mean it is so embarrassing to lay there with the doctor looking at you and touching you down there. It's so disgraceful!

CHW: (Advise based on what Emily told you)

Note to facilitator: CHW should recognize that Emily is at YIELD for a Pap test and LIGHT THE WAY by helping her overcome barriers. CHW could tell her that modesty is important but not so much that you should risk your health. CHW could stress that all women should have this normal medical procedure that allows the doctor to examine their internal organs. CHW could also recommend a female provider and tell her that she could request that a female nurse be present, which could make it more comfortable.

“Combination Connie”

CHW: Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap test screening.

Connie: A mammo-what? I don't know what you are talking about.

CHW: Advise based on what Connie told you and then transition to Pap test screening.

Note to facilitator: Connie is at STOP for mammography. CHW should WITNESS about PROS. CHW should explain exactly what is involved in getting a mammogram, where Connie can go to get one (including referrals if necessary) and why they are important. CHW then can ask about Pap test history.

Connie: Of course I get a Pap test. What woman wouldn't? The doctor automatically does it when he checks me down there.

CHW: Advise based on what Connie told you.

Note to facilitator: CHW should PRAISE Connie for taking care of her health because she is at GO for Pap test screening.

“Practicing Penny”

CHW: (Introduce yourself to "advisee" and try to figure out her stage)

Penny: I just got my Pap test last week. I was really scared that it would hurt real bad but I realized that not knowing if I had cervical cancer could hurt way worse.

CHW: (Advise based on Stage)

Note to facilitator: Penny is at GO for Pap test screening. CHW should PRAISE Penny for taking care of herself and for overcoming her fears.

“Need-a-Hand-Natasha”

CHW: (Introduce yourself to "advisee" and try to figure out STEP for mammography and then Pap tests.)

Natasha: I should get one but it's such a hassle! You'd think that the doctor's office, of all places, would have an entryway big enough for my wheelchair. But, I always have a time getting in and out. Plus, I would have to find a friend to go with me. And she needs to be a GOOD friend - someone I wouldn't mind asking to help me get my clothes on and off. And she better be strong too! It's hard work to get me up out of this chair and to keep me propped up in front of that machine.

The one time I had a mammogram, the lady wasn't very nice about calling an aide to help me stand. Then she complained that the films weren't good quality because I wasn't in a good position. I'm not sure she ever got what she needed.

CHW: (Advise based on what Natasha told you and then transition to Pap test screening.)

Note to facilitator: Natasha is at YIELD for mammogram because she knows she should go but she doesn't want to. CHW should LIGHT the WAY by suggesting questions Natasha can ask when she makes her appointment. For instance, is the building wheelchair accessible? Can someone on staff assist her through the entire exam, including dressing and standing? Does the clinic have a machine that can film a woman who is seated?

Natasha: Yes, I know I should get a Pap test, but getting onto the exam table - it's a nightmare! Ha! I'd rather have a mammogram and you already heard what I think about those!

Note to facilitator: Natasha is at YIELD for Pap screening. CHW should LIGHT the WAY by encouraging Natasha to call for an appointment because cervical cancer is preventable. Natasha should ask her provider if there is a special exam table or any special procedures in place to help women in wheelchairs have a Pap test. The CHW could offer to help make this phone call.

Witness About Benefits:

Who? Women at STOP

Why? Since they do not know any of the good things about mammograms or how early detection saves lives, women at this STEP have no PROS to balance out the CONS. This is why they aren't thinking about going for a mammogram.

How? Share personal experiences with mammography and stories about how mammograms save lives.

Light The Way:

Who? Women at YIELD

Why? Women at this STEP know the PROS of mammography, but they need help overcoming the CONS that keep them from getting one. This is why they are only thinking about going for a mammogram.

How? Talk to women at YIELD about the things that keep them from going for a mammogram and help women come up with ideas to overcome them.

Praise

Who? Women at GO

Why? Women at this STEP know the PROS of mammography outweigh the CONS. That's why they are GOING for mammograms.

How? Tell women at GO that they are doing a great job taking care of their health. Encourage them to continue going for mammograms.

CHW Training For Breast And Cervical Health

Outreach & Referral

Reaching others with the message of breast and cervical health is the purpose of outreach and referral.

Consider the following questions (brainstorm with others if possible):

Where do the women in your community go for food?

Where do the women in your community gather socially?

Where do the women in your community do their laundry?

Where do the women in your community gather?

When do the women in your community go into town?

When do the women in your community shop for groceries?

Do the women in your community go to local thrift stores?

Do the women in your community have jobs outside their homes?

On Your Own . . .

Rank the following places for your community or neighborhood. Number one is the place where you would find the most women who meet the eligibility criteria and number 16 is the location where you would find the least number of women who meet the criteria.

Next, think about why you ranked them the way you did and are any other places that you may find more women who meet the eligibility criteria?

- | | |
|----------------------------------|----------------------|
| _____ Convenience store | _____ Local Park |
| _____ Church or place of worship | _____ Wal-Mart |
| _____ Senior center in your area | _____ Gas station |
| _____ Fitness center | _____ Laundromat |
| _____ Local supermarket | _____ Beauty parlor |
| _____ Trailer park | _____ Public housing |
| _____ Other location | |

- | | |
|----------------------------------|-------------|
| _____ Sit-down restaurant _____ | (which one) |
| _____ Fast food restaurant _____ | (which one) |
| _____ Local store _____ | (which one) |

Once you know who the eligible women are and where you might locate them, what can you do to help them enroll, get screened or other kinds of helpful activities? A few ideas to keep in mind:

- Eligibility screening for the first time mammogram & Pap test
- Help arrange appointments with EWL
- Assist with transportation
- Locate female interpreters if needed
- Distribute educational materials provided by EWL in appropriate language
- Follow-up for rescreening mammogram & Pap test

How and where will you perform your work?

Faith Community

Places of faith serve an important social and service role, particularly in low-income and minority communities. Because of the significant role the church (synagogue or mosque) plays in many people's lives, it has the capability to inspire and support changes in people's health behaviors. Ways to make contact include:

- Introductory letter (budget permitting) or phone call to pastor or first lady
- Face-to-face meeting with contact
- Approval of program by religious leader or other person they select
- Set up a church (synagogue or mosque) acceptable way to meet with and teach potentially eligible women about breast and cervical health

Witness Program, Arkansas (Outreach to Increase Screening for Breast and Cervical Cancer, 1999)

In this program, African American women who are breast cancer survivors serve as role models to speak (witness) about their experience with breast cancer and to encourage other women like them to practice BSE and get mammograms.

- A witness explains how her life has changed through the experience of having breast cancer.

- The witnesses talked to women and challenged them on their reasons for not getting mammograms with the intent of persuading them to take control of their own health.

- The witnesses did not have prior public speaking experience.

- Programs were presented at churches. The first part of the program involved witnessing, followed by BSE instruction, practice time, and giving out breast health information. Participants were asked to complete a survey to give personal information, e.g., address, race and health history information.

Three months after the witnessing event, a follow-up survey was mailed to all participants. After 3 weeks, a telephone interview was conducted with those who did not reply. Although the program is labor intensive, there was a change in mammography numbers (19% of the women had one) after the witnessing program.

Workplace

Reaching women in the workplace can range from providing brochures on the importance of early detection and prevention to providing other information about programs and services available through the regional provider site and eligibility screening. Any or all these might be suitable depending on the setting, resources, needs and interests of the worksite. Also, all screening efforts should repeat the fact that it is regular *rescreening* that is most likely to reduce a woman's risk of dying of breast or cervical cancer (Outreach To Increase Screening for Breast and Cervical Cancer, 1999). Keep in mind the following points in worksite outreach:

- Use company's health nurse or other official of the company to get permission for program and to spread word of the program throughout the company using various materials (ex. posters, flyers, bulletin boards, email)
- Make program available to women during working hours (ex. lunchtime or breaks, which are usually only 15 minutes with 30 minutes of lunch)
- Make sure program information matches the participants' language and culture
- Keep it simple, make sure program is easy to understand and focuses on the importance of screenings
- Maintain privacy of women in the program

Examples: *Stores* (Wal-Mart, Dollar General, etc.), *Laundromats*, *Personnel departments* (especially in worksites that hire mainly females), *medium and small businesses* that are minority owned or whose employees represent minority groups, *schools* with a large over 50 years of age female work force, *nursing homes* with employees who have no health insurance, *service industries* (hotels, fast-food restaurants, office and house cleaning services), *meat-packing plants and farms* that employ migrant or seasonal workers, *beauty shops* that can use the "women working with women" concept to give information to employees and customers.

Partnerships

Take advantage of chances to work with organizations whose purpose and goals tie in with those of yours. Both professional and volunteer organizations can be a source of speakers, referrals, educational materials (Outreach To Increase Screening for Breast and Cervical Cancer, 1999). Check the resources listed at the end of this tool kit.

- Establish a reliable contact within the organization
- Set-up meeting with the organization and talk about your combined efforts
- Establish trust with partners, use different strengths of partners involved
- Set up place and location for the program in which both partners are able to come
- Find places and locations in which both programs will reach the most needy people of the service
- Spread word of the program around the places and areas you decide to contact
- Work as a team to accomplish all goals

Examples: African American Sororities, Sisters Network, American Cancer Society

Confidentiality

While doing outreach, clients may share very personal information with the community health worker. The CHW must be aware that her responsibility is to protect the client, yet the CHW must decide which information needs to be shared with others, such as the supervisor, or documented to communicate the client's needs. Here are some ways to help you make this decision.

1. How did the client give you the information? Was it given in confidence? Or did the client give you the information and tell you it was okay to share it with your supervisor or case manager at the provider site?
2. The CHW needs to tell the client what information will be shared with others at the provider site. If the information affects the client's health or well being, the CHW may have to tell the client of the need to share the information and with whom.

Confidentiality protects the client's right to decide who can have information about her health or life-style. It refers to the idea that one person feels reassured that the other person will not reveal personal information. Where the information is shared or not shared is also important. We must never give away personal or health information where others not involved in the care of this client could overhear the conversation. Further, sharing any information about a client with your friends in the community is certainly not appropriate.

Special Issues

Boundaries and Safety

For CHWs, maintaining personal and professional boundaries may not be easy. A CHW may feel an overwhelming sense of obligation to her community and clients that leads her to engage in activities that could be perceived as unsafe or self-sacrificing. Therefore, maintaining personal safety can be a significant issue many CHWs face in their work. This information seeks to help you honor your own boundaries and limitations. Your supervisors will have some strategies for recognizing potential struggles and support for you as you navigate boundary issues and safety hazards in the field.

Because there are few available resources or information for CHWs and their supervisors to access as they begin to explore potential professional safety hazards and effective interventions, this part of the lesson plan is based on Best Practices identified by CHWs and their supervisors during national, regional, and local CHW focused forums.

Let's establish a common language.

Common Language

Boundaries (a functional definition)

Not doing for others what they can do for themselves. With this as your philosophy, you will not get enmeshed or inappropriately involved in someone else's business.

Creating boundaries

Boundaries are limits that say: "This is how far I will go. This is what I will or won't do for you. This is what I won't tolerate from you."

Boundary distinction

The ability to differentiate clearly between self and others, distinguishing personal issues from others' issues

Appropriate boundaries

This means being able to distinguish between your personal issues and others' issues, knowing where "I" stop and "you" begin, recognizing the difference between my thoughts feelings and behaviors and the client's thoughts, feelings and behaviors

Personal Involvement

"Take responsibility for yourself, and let others do the same. Refuse to rescue."

Some potential concerns when it comes to personal involvement between the CHW and the client. Consider the following examples.

A CHW gives the client a personal loan A CHW purchases groceries for the client (will this help the client now or is the CHW teaching the client dependence?) A CHW gives a ride to a client (what are the liability issues? What is the agency policy?) A CHW participates in a client event wedding or funeral. (What does this mean to the client? What does this mean to the community? What does this mean to the CHW and to the CHW's family? Will the CHW get paid for it?)

"Don't just do something-stand there" (Blanchard, Carlos, and Randolph, 1996). Knowing when not to step in can be just as effective as stepping in. Your supervisor can help you understand when it is that the line between empowerment and dependence is crossed

Setting Limits – Including Time Limits

The first step in effective boundary distinction and effective helping is self-awareness. The very skills and qualities for which a CHW is hired can be the very skills and qualities that lead to safety concerns. Assumptions can be dangerous, ask for clarification and have a conversation together.

- A CHW has the right to say NO. Learn this concept and practice it.
- Learn to establish personal ground rules and convey them to each client.
- Be honest and direct with clients and with your supervisor.
- Consider cultural issues, e.g., what if a client gives me a gift? Should I accept or decline it? What are the consequences to the relationship with the client if I accept or decline? What do I do when offered food, dinner, a glass of wine, or a cup of coffee during the outreach activity?

Physical Space

Boundary distinction includes identification of potential helper-client relationship issues. What are some of the issues that may cause a concern specific to a CHW when it comes to physical space, especially with clients.

- What is the CHW's personal space and boundaries?
- How close does she stand to another?
- How far apart?
- How important is it to the CHW, to the client?
- What about physical contact?
- Do you like to be hugged?
- What about the client?
- What about the cultural issues?
- What about the trauma issues?
- What about religious beliefs?
- What happens when culturally, a client might be insulted if not greeted with a hug but the CHW may be triggered over past trauma if hugged?

Self Care

CHWs need to be alert to self care needs and discuss with your supervisor as necessary. Consider the following:

- The work of a CHW is emotionally draining and can be overwhelming
- Sometimes, a CHW takes too much on and gives too much of themselves
- CHWs need to have periodic conversations with supervisors about self care
- Think about eating, sleeping, and exercise habits...am I neglecting myself?
- How can I take care of myself—reading novels, fishing, bubble baths, cooking, leisurely walks, etc.
- Ask myself periodically, "What do I think will happen if..."
- Use some common sense

Transportation

Transportation is essential for clients to access services. It is also a key area for potential liability, miscommunication, and lapses or breakdowns in agency policy. The more you and your supervisor know and discuss the better.

According to the old saying, an ounce of prevention is worth a pound of cure. It is a good idea for the supervisor and CHW to plan for the worst and hope for the best. CHWs often conduct home visits or other outreach activities in remote area or dangerous neighborhoods. Trust your feelings, including fear-"a feeling of anxiety and agitation caused by the presence or nearness of danger."

Discuss the issue of letting someone know where you are at all times. Is that feasible? Not always but if possible, it may be a good idea. Build relationships with local police, business owners, neighborhood task forces, neighborhood watches, local leaders--- hanging out at a beauty shop can be a location of a safe haven, in addition to doing one on one outreach. Have a plan in place in case of emergency or a dangerous situation arises-this is when I recommend playing the 'what if..' game with your supervisor. What if your tires are slashed? What if you get a chill up the back of your spine? What if a client is cleaning his/her gun while you are conducting a home visit? What if the client has a big dog and you are afraid of dogs? What if...? Talk it out.

Physical Presentation

An up-front discussion of dress and similar issues can prevent possible tension between CHW and supervisor. A supervisor may see dress as a mark of professionalism while CHWs see it as a matter of safety or even economics. Safety issues related to community outreach activities and clothing can include missing steps or broken floorboards, scattered trash or debris, broken glass or syringes, insect or rodent infestations, animal or human waste, and the presence of animals such as dogs, cats, alligators, lizards, snakes, etc.

Communication

Communication can be defined as a mutual exchange of information and understanding. Many CHWs can enter potentially hostile "us-them" situations when they make outreach visits. Communication technology is a CHW's link to help and to the outside world. Your agency identification confirms your position in the outside world and communicates a helper status to police or other officials. It can also literally mean safe passage through apartment buildings, housing developments, and neighborhoods where residents are highly suspicious of strangers.

Environments

Tell your supervisor what you need to feel safe and why. If this isn't possible, try to identify other options that can be implemented to help accomplish the same purpose.

The agency is aware of and communicates to the CHW where potential safety hazards lie within the community, e.g., building deterioration with steps and broken windows, scattered trash around the exterior and interior of building. Can you think of other examples?

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Resources

American Cancer Society - www.cancer.org

This site by the American Cancer Society provides information about all kinds of cancer. Specifically, complimentary and alternative treatment methods, living with cancer, statistics, facts, and the latest research and news are covered.

American Institute for Cancer Research - www.aicr.org

This site provides information on cancer prevention. In addition, there are pages devoted to a nutrition hotline, a pen pal support network, funding of research grants, and consumer and health professional brochures.

BreastCancerInfo.com - www.breastcancerinfo.com

This site is maintained by the Susan G. Komen Breast Cancer Foundation and provides information on breast health, cancer treatment, events, and grants. In addition, this site also has pages devoted to survivor stories.

CancerCare - www.cancercare.org

Cancer Care is a national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance. To learn more about the free telephone educational workshops, click on Educational Programs.

Cancer Prevention and Control Homepage - www.cdc.gov/nccdphp/dcpc

This Center for Disease Control web site has information on all cancers, CDC cancer prevention programs (including the National Breast and Cervical Cancer Early Detection Program), national and state statistics and legislation, and program contact information.

Cancer Research Foundation of America - www.preventcancer.org

This site provides information on cancer research and education. It also has specific health information for women, men, and children.

Diversity Rx - www.diversityRx.org

Diversity Rx is a clearinghouse of information on how to meet the language and cultural needs of minorities, immigrants, and refugees seeking health care.

Health Resources and Services Administration's "100% Access, 0 Disparities" Campaign - www.bphc.hrsa.gov/campaign.htm

This program organizes key groups to help communities meet health care needs. This site offers examples of creative partnerships and a blueprint for action.

Healthy People 2010 - www.health.gov/healthypeople

Healthy People 2010 is a set of health objectives for the Nation to achieve over the first decade of the new century. It can be used by many different people, States, communities, professional organizations, and others to help them develop programs to improve health. Like its predecessors, Healthy People 2010 was developed through a broad consultation process, built on the best scientific knowledge and designed to measure programs over time.

Hospice Link - www.hospiceworld.org

This site helps patients and their families find support services in their communities.

Susan G. Komen Foundation - www.komen.org

This is the web site of the Susan G. Komen Foundation. This site provides information about fund-raising events, grant and funding opportunities, donations, and sponsors.

National Alliance for Hispanic Health – www.hispanichealth.org

This site provides information on Hispanic health concerns.

National Alliance of Breast Cancer Organizations -

This site provides cancer-related news flashes, bulletins, treatment and research opportunities, local support group information and an on-line calendar of events, conferences and workshops.

National Asian Women's Health Organization - www.nawho.org

This organization is working to improve the health status of Asian women through research, education, and public policy programs.

National Breast and Cervical Cancer Early Detection Program
www.cdc.gov/cancer/nbccedp/

This site provides information about the national early detection program that distributes funding to the state, territorial, and tribal programs.

National Breast Cancer Coalition - www.natlbcc.org

This coalition is a grass roots advocacy organization dedicated to fighting breast cancer. This site includes information on legislative activities, special events, advocacy training, and education and outreach programs.

National Cancer Institute's CancerNet - cancernet.nci.nih.gov

CancerNet provides accurate cancer information. It is reviewed and updated monthly based on the latest research. This site also includes a link to PDQ, NCI's cancer database which gives information on clinical trials and research.

National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Database - seer.cancer.gov

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute is the most authoritative source of information on cancer incidence and survival in the United States. The SEER registries routinely collect data on patient demographics, primary tumor site, morphology, stage at diagnosis, first course of treatment, and follow-up for vital status.

National Library of Medicine Locator Plus - www.nlm.nih.gov/locatorplus

This site allows access to a wealth of medical journals, catalogs, databases, books, and other medical research tools.

National Women's Health Information Center - www.4woman.gov This site allows access to a wealth of medical journals, catalogs, databases, books, and other medical research tools.

Patient Advocate Foundation - www.patientadvocate.org

This site can help you link to, read, and download a wide variety of women's health-related material developed by the Department of Health and Human Services, other Federal agencies, and private sector resources.

Race for the Cure - www.raceforthecure.com

This site is sponsored by the Komen Foundation. Here, information is provided about the Komen Foundation's fund-raiser," Race for the Cure"

Sisters Network, Inc. - www.sistersnetworkinc.org

U.S. Department of Health & Human Services Poverty Guidelines -
aspe.os.dhhs.gov/poverty/poverty.htm

This page provides the Poverty Guidelines established by the U.S. Department of Health and Human Services.

Virginia Breast Cancer Foundation www.vbcf.org

Virginia Center for Health Outreach at James Madison University
www.vcho.cisat.jmu.edu

Vital Options - www.vitaloptions.org

Vital Options is a not-for-profit organization using communications technology to reach every person touched by cancer.

Y-ME National Breast Cancer Organization - www.y-me.org

This organization is a monthly support group for young patients and survivors. This site provides contact and membership information as well as information for patients, friends, and families coping with cancer.

YWCA Encore Plus - www.ywcaencore.org

This program helps women get breast and cervical cancer screening

